

7-20-1990

The Next Step: Empowering California's Developmental Disabilities Community. A Study of the Lanterman Developmental Disabilities Services Act. Executive Summary Draft

Senate Health Subcommittee on Mental Health, Developmental Disabilities and Genetic Diseases

Senate Subcommittee on the Rights of the Disabled

Assembly Health Subcommittee on Mental Health and Developmental Disabilities

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Recommended Citation

Senate Health Subcommittee on Mental Health, Developmental Disabilities and Genetic Diseases; Senate Subcommittee on the Rights of the Disabled; and Assembly Health Subcommittee on Mental Health and Developmental Disabilities, "The Next Step: Empowering California's Developmental Disabilities Community. A Study of the Lanterman Developmental Disabilities Services Act. Executive Summary Draft" (1990). *California Joint Committees*. Paper 65.
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**THE NEXT STEP:
EMPOWERING CALIFORNIA'S DEVELOPMENTAL
DISABILITIES COMMUNITY**

A Study of the
Lanterman Developmental Disabilities
Services Act

EXECUTIVE SUMMARY

DRAFT

By

Senate Subcommittee on Mental Health,
Developmental Disabilities and Genetic Diseases

Senate Subcommittee on the Rights of the Disabled

Assembly Subcommittee on Mental Health and
Developmental Disabilities

July 20, 1990

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EXECUTIVE SUMMARY

The Legislature expressed its concern regarding recent trends in the developmental disabilities service system through the passage of Senate Resolution 9 and Assembly Concurrent Resolution 52 in 1989. SR 9 cites "a marked scarcity of specialized community-based services, a growing number of clients ... inappropriately remaining in or being admitted or committed to developmental centers, and a growing number of clients not receiving the services that they need to remain in community settings and develop their capacities for more independent, productive participation in society," and identifies "... inadequate and improper policies, practices, and procedures used to administer the system," as a potential cause for the system's erosion.

SR 9 and ACR 52 authorized a joint investigation of the administration of the Lanterman Act by the Senate Subcommittee on Mental Health, Developmental Disabilities and Genetic Diseases; the Senate Subcommittee on the Rights of the Disabled; and the Assembly Subcommittee on Mental Health and Developmental Disabilities. The resolutions directed the Subcommittees to issue a joint report of findings and recommendations to the Legislature. This report fulfills that mandate.

The Executive Summary lists issues raised through testimony garnered at 15 public hearings, written comments, and subcommittee research. These issues are summarized and highlighted below. Following each issue is a list of subcommittee recommendations to the Legislature.

NEEDS AND INPUT OF PERSONS WITH DEVELOPMENTAL DISABILITIES

1. **Persons with developmental disabilities lack opportunities to participate in meaningful decision-making affecting their lives.**

Recommendations of the subcommittees:

- o Regional center case managers should provide clients with information about the IPP process, and ensure as much active participation by the client as possible in development and implementation of the plan. Any materials developed for clients, relative to services, client's rights, appeals procedures, and other service systems, should be produced in a way that can be understood clearly by consumers.
- o The Department of Developmental Services should establish a vendor category to allow regional centers to purchase the services of self advocacy advisors.

- o Regional centers and area boards should sponsor training sessions to assist persons with developmental disabilities in developing self-advocacy skills in a number of areas, including:
 - a. IPP development,
 - b. Choosing appropriate living settings,
 - c. Choosing appropriate work training and employment opportunities,
 - d. Opportunities for becoming a board member on various developmental disabilities organizations,
 - e. Understanding the service system, and
 - f. Long-range and transition planning.
 - o The Legislature should amend the Lanterman Act to include a more expanded value statement relative to the importance and necessity of involving and empowering consumers as much as possible.
2. **Boards of organizations serving persons with developmental disabilities lack adequate representation from those they serve.**

Recommendations of the subcommittees:

- o The Legislature should amend the Lanterman Act to specify distinct and separate board seats for persons with developmental disabilities on the State Council on Developmental Disabilities, local area boards for developmental disabilities, and regional center boards.
 - o The board to which any developmentally disabled person is appointed should take responsibility for providing training on the functions and operations of the board, and for providing an assistant to help ensure consumer participation. Moreover, these boards should orient the remaining members on ways to ensure full participation by the consumer representative.
3. **The segregated workshop setting, consisting primarily of "piece-work," is an outdated model of a work program which does not reflect work experiences enjoyed by other workers.**

Recommendations of the subcommittees:

- o The Departments of Rehabilitation and Developmental Services should develop a joint workplan on ways to increase the number of supported work opportunities available to persons with developmentally disabilities, with emphasis on creating a wide range of opportunities, including part-time supported employment and jobs that can be held by persons with severe disabilities.

They should consult with state and local chambers of commerce to find out the best ways to encourage private industry and businesses to fill jobs with clients in supported employment.

- o The Legislature should work with Congress to develop less rigid transition policies between SSI dependence and employment, which address the provision of health and other benefits.
 - o Local linkages between developmental disabilities service organizations and community job markets need to be developed, in order to take advantage of opportunities for integrated and supported employment. These linkages should be the responsibility of the regional center, the local Department of Rehabilitation field office, and public and private employment services including local offices of the Employment Development Department.
4. There are many barriers to establishing more independent living situations for persons with developmental disabilities.

Recommendations of the subcommittees:

- o The State Council on Developmental Disabilities should address the issue of inadequate numbers of affordable housing options for persons with developmental disabilities, along with recommendations for increasing housing options, in its annual state plan, after consultation with public and private housing authorities and experts.
 - o New funding options for retrofitting homes and apartments for accessibility should be investigated, when such retrofitting will result in the ability of a person with developmental disabilities to move from a more restrictive setting. Funding sources that might be considered for this option might include the Program Development Fund, or regional center funds earmarked for residential placement.
 - o Case managers for persons with disabilities who live in independent settings should determine whether there are full-time managers on-site to provide assistance when needed, such as in emergencies. If there are not, the case manager should attempt to make alternative arrangements to cover emergency contingencies.
5. Support services which assist persons in achieving maximum independence, and adequately-trained persons to provide these services, are scarce.

Recommendations of the subcommittees:

- o Clients should have the option of dismissing attendants who are not providing reliable or quality services, and should be involved as much as possible in the selection of attendants who will serve them.
 - o Regional centers should consider establishing minimum standards and qualifications for attendants, as a condition of vendorization, whether the attendant works for an agency or independently. Other persons with disabilities should be considered as potential attendants and client assistants, to provide practical training and assistance to developmentally disabled persons living in the community.
 - o The Association of Regional Center Agencies should develop model community support programs that would result in more independent and integrated lifestyles, for purposes of funding with purchase-of-service funds, or Program Development Funds.
- 6. Persons with developmental disabilities lack essential services and opportunities including transportation, recreation and socialization, and family support services.**

Recommendations of the subcommittees:

- o Local transportation plans should be reviewed carefully by area boards and regional centers to ensure that both existing and new services will be accessible to, and usable by, persons with disabilities.
- o Local advocacy organizations, in conjunction with regional centers, should seek to develop opportunities and working relationships with generic community agencies that provide recreational and social programs, with the aim of integrating persons with disabilities. Workshops and seminars, sponsored by local organizations such as area boards, regional centers, or parent advocacy organizations, and including consumer self-advocacy groups such as People First, should be held to provide a forum for discussions on friendships on the job and in the community, and on dating, sexuality, marriage, and childrearing.
- o Family members should be encouraged to be case managers where it is desirable for the client. All parents should be offered classes designed to assist them in understanding and accepting their child's personal and health needs

ETHNIC ISSUES

1. Multilingual services are necessary at IPP meetings, and with appointments with physicians, school personnel, and other providers.

Recommendations of the subcommittees:

- o Regional centers should increase their recruitment efforts to hire case managers who can provide necessary multilingual services. In the event that hiring of staff with specific linguistic skills may not be warranted due to a small number of clients representing a specific ethnic population, regional centers should contract with organizations or individuals that understand the developmental disabilities system and that can provide bilingual and bicultural services.
 - o After assessing ethnicity in various regional center catchment areas, the DDS should provide technical assistance, as well as funding where necessary, to ensure that affirmative action programs are implemented at the local level.
 - o An Office of Minority Affairs should be established within either DDS or within the Health and Welfare Agency to oversee affirmative action programs and the development of written materials.
2. Regional centers and other service agencies vary greatly in the kinds of written material they provide to families about their services, and many lack written material in languages other than English.

Recommendations of the subcommittees:

- o It is desirable for regional centers to vary in the types of information they publish relevant to the services they provide, since regional centers need to adapt their materials and programs to the service needs of the communities they serve. At the same time, there exists a need for consistency in the types of basic information that is given to families and clients. There is also a necessity to address how extensively multicultural and multilingual information needs will be met, within limited regional center resources.
- o The Association for Regional Center Agencies should assess their unmet need for multicultural and multilingual informational materials, and should develop plans for meeting these needs, with assistance from the State Council on Developmental Disabilities.

3. The cultural and religious beliefs of families, such as differing nutritional habits, or differing views on whether it is considered acceptable to place a handicapped child outside the home, impact service planning. Additionally, farmworkers and other undocumented persons may be concerned about their legal status if they seek assistance from regional centers.

Recommendations of the subcommittees:

- o Regional centers, area boards, and the department should make specific outreach efforts to undocumented or underserved populations, utilizing peer outreach workers in order to establish trust.
 - o When case workers interact with families from other cultures in order to plan services for the family and client, they should understand the cultural and religious beliefs that may impact service planning. To develop a resource for the case worker and the family, the regional centers should encourage the formation of family organizations that can provide peer assistance about the California developmental disabilities system. Then, when necessary, case workers can seek the assistance of these organizations to encourage full participation of the family in client service planning.
 - o Funding should be provided to area boards to coordinate seminars and training sessions to empower ethnic group parents to become active advocates and partners on the planning team relative to their childrens' needs.
4. Community residential, day, and support services which are sensitive to cultural and language issues, are extremely difficult to locate.

Recommendations of the Subcommittees:

- o Area boards and DDS should develop and approve Program Development Fund proposals that address services to multicultural and multilingual client populations.
 - o Regional centers should ensure that the process of developing IPP's includes consideration of culturally-relevant service modalities, including such services as at-home and community-based recreation and training programs.
5. Because many ethnic minority families live in poverty, environmental factors can contribute to a higher incidence of developmental disabilities.

Recommendations of the subcommittees:

- o Prevention programs specifically targeted at low-income ethnic minorities should have a high priority.
6. Data are not available which give an accurate picture of the size of different ethnic groups in the state and within each regional center catchment area.

Recommendations of the subcommittees:

- o In order to adequately plan service needs, DDS and regional centers should routinely assess the changing composition of ethnic diversity among developmentally disabled persons in the state.

ADVOCACY

1. It is often unclear to individuals in need of advocacy services where to find appropriate assistance due to duplication of services, gaps in services, and lack of information.

Recommendations of the subcommittees:

- o There is a need to clarify the roles of various advocacy organizations in order to reduce duplication, maximize effectiveness in meeting California's advocacy needs and reduce public confusion over what advocacy services are available to them.
2. Increasing advocacy needs and caseload growth have not been matched by increased funding. Conditions on federal funding restrict the effectiveness of some advocacy organizations.

Recommendations of the subcommittees:

- o Advocacy staffing ratios should be based on a formula which reflects growth in the developmentally disabled population as well as geographic areas of responsibility.
 - o A review of federal and state mandates should occur to determine if federal funding alone is adequate to meet these mandates.
3. System monitoring and investigation is inadequate.

Recommendations of the subcommittees:

- o Define the authority and access of area boards in conducting independent systemic monitoring and review.

- o Define the authority and access of PAI in conducting investigations into alleged abuse.
- 4. Effectiveness of advocacy boards has been hampered by long delays and politicizing of appointments to the boards.

Recommendations of the subcommittees:

- o Include strict eligibility requirements for advocacy board members as well as timely appointments by the Governor.
- o Exclude representatives of State Agencies from serving as voting members of the State Council.
- 5. Clients' Rights Advocates within regional centers and developmental centers have a perceived conflict of interest as they are employed by a service delivery agency.

Recommendations of the subcommittees:

- o Clients' Rights Advocates within the regional centers and developmental centers have an inherent conflict-of-interest when required to advocate against the organization by whom they are employed. Therefore, the CRA function should be either transferred or contracted out to an independent agency.
- 6. An increasing use of attorneys by regional centers in fair hearings and appeals has increased the need for advocates with legal expertise, formalized the appeal process and shifted expenditures away from services.

Recommendations of the subcommittees:

- o The use of attorneys at informal appeal hearings should be prohibited.

REGIONAL CENTERS

- 1. Eligibility criteria is applied differently throughout the state, so that an individual receiving services through one regional center may be deemed ineligible by another. Regional centers have difficulty in meeting the required 15 day deadline for holding the initial face-to-face interview to begin the intake and assessment process and the mandated 60-day deadline for completing the intake process (IPP development).

Recommendations of the subcommittees:

- o The State Council on Developmental Disabilities should explore and propose methodologies to reduce disparities in eligibility requirements. The 36-month cut-off age for infants at risk should be eliminated so that services are provided as long as a child remains at risk.
 - o The core-staffing formula for regional center intake and assessment should be reviewed to determine if it still adequately meets the needs of this population.
 - o Planning should begin to project and assess the needs of new populations of persons with developmental disabilities.
2. **Regional centers have serious problems in developing adequate individual program plans (IPP).**

Recommendations of the subcommittees:

- o IPP's should be developed to reflect all the service needs of the client. This should include a discussion of unmet needs. DDS regulations should be reviewed to ensure adequate evaluations of regional center IPP's. Corrective steps should be required and monitored for regional centers which inadequately develop and review client IPP's.
 - o All client plans should be jointly developed between all service providers and reviewed to ensure consistency in meeting client needs.
 - o IPP's should define needs in measurable terms which are designed to move clients toward greater independence whenever possible.
3. **Significant increases in regional center clients; increased task and responsibilities for case workers; and a high staff turnover, have not been factored into the caseload size of regional center case managers. Parents have not been encouraged or trained to be case managers for their children. The instability of assignment of client to case manager often results in a lack of familiarity with client and family needs.**

Recommendations of the subcommittees:

- o Case management case loads should be capped at a level which allows a maximum level of involvement with the client, understanding of client needs and the ability to meet those needs.
 - o Continuing education and training of case workers should be funded.
 - o Parents should be encouraged to become program managers when appropriate and regional centers should provide adequate training and support to all CPC's.
 - o Since regional centers should ensure the delivery of service, regardless of lead agency responsibility, deactivation of cases should only occur with the expressed consent of the client and/or family.
4. Regional center quality assurance expectations are not clear and standards and regulations are often applied differently between regions. Regional center requirements often conflict with licensing requirements laid down by other agencies.

Recommendations of the subcommittees:

- o Licensing and regional centers should work together to reduce conflicts in program requirements. A system of conflict resolution should be developed by interagency agreement between the Department of Social Services and DDS.
 - o Quality assurance guidelines should be developed and enforced to reduce the possibility for misuse of placement and monitoring authority of the regional center. Every effort should be made to minimize disruptions to client services when facilities close. Program standards should be based on client outcomes.
5. Public information and education; outreach and casefinding is not accomplished to the degree necessary to ensure persons with developmental disabilities and their families are made aware of available services.

Recommendations of the subcommittees:

- o Information and training should be provided to non-system personnel who are in referral positions especially the medical and educational communities.
- o DDS should develop a plan and tools for statewide outreach and education, including the development of consumer friendly, multi-language materials.

- o Regional center funds should be specifically earmarked for information and educational services.
 - o A concerted effort should be made to ensure that outreach and education is occurring within minority communities.
6. **Communities lack a broad range of programs and services required by persons with developmental disabilities and families, despite the regional centers' mandate to develop new community resources.**

Recommendations of the subcommittees:

- o Re-evaluate the formula for new programs to ensure funding adequately reflects program costs. Funding formulas should allow for differential costs in various statewide and local geographic regions.
 - o PDF funds should not be used to bail out existing programs.
 - o PDF should favor the development of integrated programs.
 - o DDS and the regional centers should develop a strategic planning model to better determine client needs and estimate related costs for meeting these needs.
7. **Little innovation in programming occurs and regional centers primarily provide services within a limited number of DDS approved service categories, despite their mandate to develop innovative programs.**

Recommendations of the subcommittees:

- o Testing of alternatives to existing placement models should occur including, but not limited to, a voucher system, professional parent model, foster families, professional roommate program, and supported independent living.
8. **An open-ended entitlement system creates inherent conflict for regional centers which provide services within a closed-end budget. DDS budget practices are out of sync with the legal mandates of the Lanterman Developmental Disabilities Services Act.**

Recommendations of the subcommittees:

- o ARCA and DDS should develop methodologies to better predict and address budget deficits without transferring direct service dollars to purchase of service.

- o DDS should develop its budget based on the full implementation of IPP's.
 - o ARCA, SCDD and DDS should jointly develop a strategy for identifying and addressing the budget needs of existing unserved and underserved populations.
 - o The payment of services should be done by a centralized agency to eliminate the conflict inherent in having the regional center both identify and fund services to meet client needs.
9. Individuals with developmental disabilities, their families and service providers are concerned that regional centers have become overly bureaucratic in their performance and relationship with their clients. Additionally, concerns were raised relating to the increasing hardship caused to staff, clients and providers by inadequate core staffing formulas.

Recommendations of the subcommittees:

- o DDS should review the cost of providing office space to regional centers and determine if it is reasonable.
- o Stricter criteria should be developed to ensure that regional center boards adequately represent the constituency groups they serve. This should include mandating client representation on all regional center boards.
- o All staffing formulas for regional centers should be review and modified to ensure adequate staff resources exist for regional centers to meet their mandates.

COMMUNITY RESIDENTIAL PROGRAMS

1. State-paid rates to residential care providers do not reflect the cost of providing residential services.

Recommendations of the subcommittees:

- o Rates paid to residential care providers must reflect the actual costs involved in providing stable, quality services and should reflect the commitment to ensuring that community residential facilities are well integrated throughout California and within communities.
- o DDS should explore the possibility of securing federal funding to support the continuum of care necessary in the community.

- o DDS should determine the necessary start up costs involved in developing new community programs and provide necessary funding, either through PDF grants, low-cost loans, interest free loans, and or the leasing of state-owned properties.
2. A variety of agencies with licensing and monitoring responsibility conflict in their directive to care providers.

Recommendations of the subcommittees:

- o A mechanism for resolution of conflicts between regulatory agencies must be developed and regulations must allow for the flexibility necessary to address the individual needs of each client.
3. The residential care system is lacking in both stability and quality.

Recommendations of the subcommittees:

- o Program structure and staffing levels must reflect individual client needs as identified in the IPP, should be client-outcome motivated and geared toward transition planning whenever appropriate.
 - o DDS should pilot small, community-based and integrated residential programs which service clients with serious behavior or medical issues and which are state-owned and operated and state-owned and leased.
 - o DDS should provide targeted technical and financial assistance to non-profit organizations who wish to establish community residential programs.
 - o DDS and regional centers should develop training and recruitment programs for direct care staff, including joint efforts with institutions of higher education, state-funded training programs and mentor-facility programs.
 - o A full examination of ARM should be conducted to determine if it adequately addresses quality and funding issues and if it advances California in the provision of least-restrictive settings and services.
 - o DDS must make the provision of community residential services for children a priority.
4. The system is lacking in the program flexibility necessary to accommodate the very individualized needs of persons with developmental disabilities.

Recommendations of the subcommittees:

- o The services available to persons with developmental disabilities in the community should provide a full range of options designed to move clients toward the least restrictive setting and service needs. Services must be flexible and able to meet individual client needs.
 - o DDS should pilot a variety of alternative service models, including "professional parent" and foster parent models, professional roommate model, expanded in-home and other support services designed to preserve the family home structure and support independent living, as well as the creation of crisis intervention and Level 4 facilities designed to reduce developmental center placements.
5. DDS has not developed mechanisms for realistically projecting future needs and planning for future needs is often overshadowed by the need to react to crisis situations.

Recommendations of the subcommittees:

- o DDS and regional centers must improve their methodology in collecting data which would assist them in early identification of future needs. Placement of new programs must relate to the availability of necessary support services.

DEVELOPMENTAL CENTERS

1. According to testimony from the Department of Developmental Services (DDS), between July 1988 and September 1989, 338 children were admitted to developmental centers. Of these, 53% were admitted for behavioral issues. These figures indicate a marked increase in the admission of non-medically involved children and has raised many questions for families and advocates, concerning the appropriateness of developmental center placements for children, adequacy of staffing, and whether the admission of children to the centers point to inadequate community and family support.

Recommendations of the subcommittees:

- o Require DDS to immediately develop a timely plan for the permanent placement of all non medically-involved children into the community. This should include appropriate and flexible family supports and the exploration of alternative community residential models.

- o A long-term plan for providing services to behaviorally difficult children should be developed and should include technical assistance programs to residential care providers, crisis intervention programs, state-intervention for facilities at risk of closing, early detection and intervention for children at risk, and interagency agreements to ensure licensing standards are conducive to children.
 - o While children remain in the developmental centers, DDS should require appropriate staff training, maximize opportunities for integrated activities within the community, and take other steps necessary to minimize the adoption of "institutionalized behavior" which may reduce the chance for a successful community placement.
2. A lack of appropriate and stable residential facilities to meet the needs of adults has resulted in persons being inappropriately admitted to and remaining in developmental centers.

Recommendations of the subcommittees:

- o The community care system should be stabilized by ensuring the adequate and appropriate facilities exist to serve the varied needs of developmental center residents.
 - o State owned and operated and/or state owned and leased community care facilities should be created.
 - o Fair rates should be set for community care providers to improve quality and stability.
 - o A more complete discussion and related recommendations concerning stability and quality of community care facilities can be found in the chapter devoted to community residential programs.
3. The cost for care in the developmental centers is significantly higher for the taxpayer when compared to community placement or the cost of family support if the child lives at home.

Recommendations of the subcommittees:

- o The state should pursue federal payment for the placement of developmental center clients into the community.
- o Regional centers should bear the cost of developmental center placements.

4. Serious questions have been raised as to the adequacy of established staff-to-client ratios, as well as staff training, in a number of programs within the developmental centers.

Recommendations of the subcommittees:

- o The time and motion study for developmental center staff proposed by DDS should be done. DDS should propose appropriate changes in their staffing formula to reflect the findings of such a study.
 - o DDS should develop an ongoing training program for developmental center staff to ensure they employ appropriate and progressive treatment as well as identify early signs of abuse and mismedication.
5. Developmental Center lands have been threatened with piecemeal disposal without any gain for persons with developmental disabilities.

Recommendations of the subcommittees:

- o The Legislature should approve a plan to sell or lease excess developmental center land only if the proceeds are targeted to provide community and family support services.
- o Residential programs approved for placement on excess developmental center land should only be approved if they offer an integrated setting.

DAY PROGRAMS/WORK TRAINING PROGRAMS

1. Current data and evaluation systems do not accurately track client gains in different types of programs offered through regional centers, inhibiting the development of innovative program models.

Recommendations of the subcommittees:

- o The effectiveness of day and work training programs should be measured by client outcomes including increased competencies, client participation in selected activities and work programs, and ability to participate in community-based training and employment.
- o Regional centers should place persons into integrated and non-handicapped work environments whenever possible. The state can assist by providing incentives to both small and large businesses to incorporate handicapped persons into their work force.

- o To the extent that current vendor categories approved by DDS do not reflect supported work options, or other innovative work training and placement options, they should be changed, either administratively or statutorily. Alternatively, the Legislature should consider the elimination of vendor categories altogether, in lieu of a more flexible, local approval procedure, to ensure the greatest amount of flexibility and creativity in developing client-centered programs.
2. Program success is hampered by a lack of available staff development opportunities; weak and inconsistent quality assurance standards; a lack of self-advocacy strategies in planning; and poor coordination and planning with local school districts to develop transition opportunities for employment.

Recommendations of the subcommittees:

- o DDS should develop regulations which reflect a statewide commitment to client self-determination, integration, staff development, quality assurance, and other components of a system dedicated to providing persons with developmental disabilities productive and independent lives in the community.
 - o DDS should standardize quality assurance. Rates paid to direct care providers, such as job coaches, should be competitive to attract and retain knowledgeable and trained personnel.
 - o DDS, the Department of Education, regional centers and local school districts should jointly determine methods of assuring integrated transition employment training and opportunities.
3. Priority for funding is not given to the establishment and continuation of supported employment and other community-based work training and employment options for persons with disabilities. Funding priorities do not take into consideration transition between school or work training and employment programs as well as support services necessary to enable persons with disabilities to obtain and maintain community-based employment.

Recommendations of the subcommittees:

- o New programs, such as supported employment of persons with disabilities in community-based work sites with support and assistance, should become models of future funding and placement priorities, for the department and for regional centers.

- o Developmentally disabled persons, and their families, may need corollary services to assist them in participating successfully in work programs. Such services may include components such as family support, transportation to and from the job, money management skills training, and socialization skills to help them develop friendships at work.
- o Cost of living adjustments are essential components of an adequate funding system. These should not be negotiable items every year in the budget; denying these small increases merely results in the closure of programs and the continuing turnover of dedicated and experienced staff.
- o The Legislature should work with Congress to ensure that obtaining a job does not result in the loss of essential federal benefits, unless these benefits can be obtained along with employment. Moreover, if the job is lost, federal and state benefits should be immediately reinstated. If the benefit package is placed at risk when employment opportunities are offered, clients will have little incentive to risk taking a job.
- o The public school system should start client transition planning several years before the student leaves school. The regional center should encourage the coordination of the Individual Program Plan (IPP) and the Individual Education Plan (IEP) during this time, along with continuing involvement of the client and his/her family, to make this transition as smooth as possible. DOR should also be involved with this planning process during this time, to the extent that its day, habilitation, or supported employment programs are compatible with and desired by the client and family.

FAMILY SUPPORT

1. **Despite a California Supreme Court decision reasserting service entitlements, family support services continue to be budgeted as though they are discretionary and subject to historical administrative controls.**

Recommendations of the subcommittees:

- o Family support services that help families keep their developmentally disabled son or daughter at home, such as respite care, transportation, parent training, counseling, after-school programs, and recreation,

should be budgeted with the same allocation methodology as other services. High value should be placed upon funding those services that enable a family to remain together.

- o Since respite care is the family support service most often requested by parents, this service should be expanded to meet the need. The cost of additional hours of respite care would be far less than the cost of placing the child in an institutional setting.
2. Vendorization categories are often too restrictive to allow services necessary to adequately meet the needs of families.

Recommendations of the subcommittees:

- o Each family's needs are different. Some families need additional respite care. Others need after-school care for their son or daughter. Another family may need only a washing machine and dryer to enable them to cope with the added pressures and needs of a child with severe disabilities, while yet another family may need parent training and counseling to deal with the particular needs of their situation.
 - o A more flexible system is needed to allow the purchase of a wider range of support services individually tailored to meet the needs of families, without the bureaucratic restrictions that currently prevent these options. Parent voucher systems and other funding models should be developed and evaluated for their ability to present a wider range of services to parents who choose to keep their children at home.
 - o DDS should recognize alternative models of respite care, including the use of individual respite workers, including parents and senior citizen volunteers as respite providers.
3. Few providers exist to provide parenting skills and sexuality training, including information on sexually transmitted diseases such as AIDS, to enable persons with developmental disabilities to lead lives similar to the nondisabled population, including personal and sexual relationships, marriage, and raising a family.

Recommendations of the subcommittees:

- o Families and clients need more training in the area of sexuality, both to ensure safety for the client, and also to ensure family confidence in the client's ability to address relationship issues that will arise in a community-based environment.

- o Regional centers should assist advocacy organizations to develop parent training programs for developmentally disabled parents. Child Protective Service agencies should be prepared to assist these families through referrals to support agencies, rather than presuming that a child of developmentally disabled parents is automatically at higher risk of neglect.
4. Regional center case managers may fail to inform parents of the scope of services that are available. Parents are often intimidated by professionals and decisions may be made without parental input.

Recommendations of the subcommittees:

- o Every regional center should offer information to the parent about local parent advocacy organizations, the provisions of the Lanterman Act, the procedure for developing and implementing and Individual Program Plan, and applicable appeals procedures. This information should be given several times during the first year that the parent is a client of the regional center system, and routinely thereafter, such as during IPP meetings.
 - o All agencies that provide services to developmentally disabled persons should include parents in the development of program and treatment plans. This is a philosophical issue as well as a client's rights issue. This emphasis starts with the commitment by the Administration to the appointment of agency and department directors who support the concept of family participation in the development and implementation of client plans.
 - o When desired by families, parents should be encouraged to become case managers for their children. The Lanterman Act should be amended, if necessary, to encourage parental case management as a family option.
5. According to DDS, 75% of case managers working with families report an insufficient number of generic services to meet the needs of families who keep their children at home.

Recommendations of the subcommittees:

- o For a discussion of the subcommittees' recommendations regarding improved coordination and provision of generic services, see the chapter devoted to systems coordination.

6. Difficulties were reported in obtaining non-segregated services, necessary for life skill training and in transition to adult life, from community providers, such as schools, day care providers, preschools and recreational facilities. Quality services from physicians and dentists are also difficult to locate in the community.

Recommendations of the subcommittees:

- o Integrated settings, important for all persons, including those with developmental disabilities, are particularly valuable for children, since such settings improve the possibility of independence in adulthood. Discrimination by community care providers, based on disabilities, should be prohibited. Education and training of community care providers should be provided.

DUAL DIAGNOSIS

1. There is not a statewide standardized definition of dual diagnosis and the psychiatric problems of this population may not be recognized in a timely manner. Consequently, clients may be referred to the mental health system with inaccurate diagnoses. Further, our ability to accurately identify all those persons who are in need of dual services is significantly hampered by conflicting diagnostic criteria and ineffective data collection. According to DDS, approximately 8% of regional center clients meet the definition of dually diagnosis. However, the Association of Regional Center Agencies (ARCA) places this figure at approximately 20%.

Recommendations of the subcommittees:

- o Review the MOU between DDS and DMH, as well as regulations of both departments, to determine their effectiveness in mutually defining this population.
 - o Seek funding sources for research relating to the creation of appropriate diagnostic and treatment tools.
2. Although DDS has an agreement with DMH, whereby persons with developmental disabilities in need of mental health services shall have access to treatment, no funds are appropriated. Additionally, neither system has been funded for a coordinating staff position, resulting in inconsistent application of the Memorandum of Understanding (MOU) throughout the state.

Recommendations of the subcommittees:

- o Fund mental health/developmental disability specialists for regional centers and local mental health agencies.
 - o DDS and DMH should jointly endeavor to seek federal funds for the treatment of persons with dual diagnoses in the community.
3. There is a need for an appropriate continuum of residential services, including placement facilities for clients ending 72 hour involuntary commitment, community-based crisis intervention, post crisis treatment programs, and family respite programs. Without such community options, many individuals with a dual diagnosis become homeless or eventually find treatment only in the developmental centers, some under a penal code commitment.

Recommendations of the subcommittees:

- o Implement the ARCA Mental Health Task Force recommendations, including the establishment of a pilot Regional Transitional Facility(s) to provide comprehensive services to persons with dual diagnoses.
 - o DDS should support the development of respite programs to serve this population.
4. There are fundamental differences in philosophies and structures between the developmental disability and mental health systems. The developmental disabilities service system entitles clients to services but prohibits the regional center from providing services available from a generic agency. The mental health system is not an entitlement system and increasingly has determined to serve only select categories of persons with mental health needs. Both systems are hindered by limited resources.

Recommendations of the subcommittees:

- o Amend the Lanterman Act to allow regional centers to purchase services when conflicts over jurisdiction threaten the timely delivery of services. Conflict resolution should include the payback for services provided whenever it is determined that a generic agency has service responsibility, as well as a plan for the orderly transfer of that responsibility.

- o DDS and DMH should provide leadership in fostering ongoing communications between local service agencies.
 - o DDS caseload funding should reflect the need of intensive case management for persons with dual diagnoses.
5. There is an inconsistent approach to the acceptance of responsibility for dually diagnosed clients within the education system.

Recommendations of the subcommittees:

- o AB 3632 should be amended to specify the responsibilities of local mental health and educational agencies in providing mental health evaluation and treatment to students with developmental disabilities.
6. There is a scarcity of data regarding the mental health needs of regional center clients and utilization of existing mental health resources. This makes it impossible to accurately plan for appropriate services.

Recommendations of the subcommittees:

- o DDS, DMH, and local service agencies should review the methodology used to collect relevant data and modify it as necessary to ensure appropriate and accurate data are available to assist in resource planning efforts. The needs of persons with dual diagnoses should be address in all related planning cycles.
7. Cross-agency training and training for community service providers regarding dual diagnosis does not exist.

Recommendations of the subcommittees:

- o Local agencies should develop cross-agency training programs, as well as training programs for community service providers.
 - o Developmental disability system representatives should serve on county mental health advisory boards and mental health system representatives should serve on regional center and area boards. A similar cross representation should occur on state boards.
8. There exists a significant shortage of adequately trained professionals serving persons who are dually diagnosed.

Recommendations of the subcommittees:

- o Continuing education training should be required for professionals in the field of mental health and developmental disabilities. DDS and DMH should work with local service agencies and institutions of higher education in developing curricula designed to recruit and train professionals.
9. There is an inappropriate prescribing of psychotropic medication for behavioral control rather than to reduce symptoms of serious mental disorders.

Recommendations of the subcommittees:

- o DDS and DMH should jointly develop a mechanism to provide guidelines for the administration of psychoactive medications to persons with developmental disabilities. Local procedures for the monitoring of the administration of psychoactive medications should be developed.
 - o Training for community and institutional care providers should be provided.
 - o Requirements for obtaining informed consent from clients and/or their conservator or guardian should be reviewed to insure that complete disclosure of the effects of medication, and the alternatives, is made.
10. Procedures for involuntarily committing a person with a dual diagnosis to a psychiatric hospital or developmental center often impede placement in a proper treatment facility.

Recommendations of the subcommittees:

- o Welfare and Institutions Code Section 6500 and the Lanterman-Petris-Short should be reviewed to determine if significant barriers to necessary involuntary treatment exist.

NEW POPULATIONS

1. New and emerging populations require services from a variety of state and local agencies. With escalating costs, coordination and a clear delineation of who provides what services is essential. However, a lack of coordination and disputes over responsibility between agencies result in delayed and/or denied services. Services may vary from county to county as well as between different regional centers. Many who are eligible for services are unaware that they exist or do not know how to access the system.

Recommendations of the subcommittees:

- o State and local agencies should develop forums to foster communication, timely conflict resolution and early discussion of emerging issues. Regional centers should have representation on all bodies which address these populations.
 - o Primary responsibility for case management and service delivery should be assigned to regional centers. Agencies with shared responsibilities should jointly participate in individual program planning. Where the provision of a generic service is in dispute, regional centers should be authorized to provide that service. A methodology should be developed for reimbursement of cost and transition of service provision when another agency is found to be responsible for a specific service.
 - o MOU's between state and local agencies must be developed and enforced wherever shared service responsibility exists. State agencies should submit annual reports to the Legislature on the effectiveness of MOU's, as well as a discussion of continued areas of dispute.
 - o Regional centers should have the targeted funding necessary to ensure aggressive and culturally sensitive outreach is occurring to eligible individuals and families.
2. Comprehensive case management needs of HIV positive children are not being met by the CCS HIV Children's Program, the medical HIV Centers or the regional centers. The model case management system within the regional centers is stymied by the excessive caseloads which prevent adequate attention to this population's special needs.

Recommendations of the subcommittees:

- o Regional centers should be designated as the primary service agency for AIDS/HIV infected children. Adequate resources should be allocated to ensure appropriate case management services, as well as necessary direct services, are provided. DDS should pursue a Title 19 case management waiver for service to this population.
- o The CCS HIV Children's Program should be reviewed for effectiveness in meeting the needs of it's targeted clientele. CCS regulations should be reviewed to determine if they are exclusionary.

3. There is a lack of funding to regional centers for AIDS prevention education and training needs.

Recommendations of the subcommittees:

- o AIDS prevention must be a high priority for regional centers. Necessary funding and educational/training resources should be provided to regional centers by DDS.

The ARCA AIDS Education Project should be continued and expanded to ensure appropriate training of regional staff, vendors and clients is occurring.

4. Current confidentiality laws relating to AIDS and HIV infection cause confusion among administrative and program personnel within the regional center system as to what procedures should be followed for testing, release of test results and consent for treatment.

Recommendations of the subcommittees:

- o Training for regional center staff, health care professionals and other service providers should include information and guidelines regarding confidentiality laws relating to AIDS testing and release of test results.
- o Confidentiality laws were not designed to exclude persons with AIDS/HIV infection from necessary services. Laws should be reviewed to ensure this is not occurring while maintaining the highest possible degree of privacy.

5. Recruitment of community service providers for AIDS/HIV positive clients is difficult.

Recommendations of the subcommittees:

- o The subcommittees oppose any attempt to treat persons with AIDS/HIV infection differently under the law except as necessary to ensure privacy and secure necessary and desirable services.
- o Regional centers should take steps necessary to ensure clients with AIDS/HIV infection are not subjected to discrimination or denial of services. This should include appropriate training of regional center staff and direct care service providers. Additionally, regional centers should actively recruit vendors who will provide integrated services to this population.

6. Substance exposed infants are subject to delays in receiving needed services. The implementation of the current state definition of developmental disability does not qualify a child exposed to drugs in utero for infant services. The required documentation that the child is substantially delayed is difficult to obtain for any child under the age of 18 months. By this time, the child has outgrown infant programs and may be deemed ineligible for services.

Recommendations of the subcommittees:

- o Services should begin as soon as a substance exposed infant is identified, including pre-birth. The 36 month cut off for services to at-risk children should be extended. Services should continue as long as a child remains at risk.
7. Families in which there is substance abuse are difficult to locate or unwilling to cooperate in intervention programs.

Recommendations of the subcommittees:

- o Greater efforts must be made to identify substance exposed infants. Regional center staff should be trained in outreaching to families vulnerable to substance abuse. Information about regional center services should be provided to every medical professional who has regular contact with pregnant women and new parents.
8. Excessively large regional center caseloads make it difficult to provide the intensive case management necessary to meet the needs of non-traditional categories of persons with developmental disabilities.

Recommendations of the subcommittees:

- o Staff-to-client case loads should be limited in order to ensure necessary case management services are being provided to meet the needs of individual clients and families.
9. California public policy does not adequately support in-home care for technology dependent children despite a clear fiscal benefit to the state.

Recommendations of the subcommittees:

- o Rates for all in-home client and family support services should be reviewed to ensure they are equitable and competitive. DDS should pursue expanded Medicaid waivers for in-home services to technology dependent children.

- o Regulations which restrict family members and lay practitioners from performing basic medical procedures should be reviewed and revised to ensure they do not result in the unnecessary placement of children into more restrictive settings.
10. Non-institutional out-of-home alternatives for the technology-dependant are scarce. Furthermore, community care licensing regulations often frustrate placement for those having recurrent nursing needs.

Recommendations of the subcommittees:

- o DDS should develop a course of action to increase the availability of community-based residential and day services to technology dependent and medically fragile children, including but not limited to, state owned, operated and/or leased residential facilities; the speedy development of ICF/DD-N regulations; and the development of a funding methodology which adequately compensates care providers.
 - o Community care licensing regulations should be reviewed and revised to ensure they do not restrict the placement of technology-dependent and medically fragile children into community programs.
11. Private and public insurance have exclusionary policies and limitations.

Recommendations of the subcommittees:

- o A state task force should be established to develop ways to improve insurance coverage of medical and support needs for children with developmental disabilities are met in the least restrictive environment.
12. Opportunities for age-appropriate activities and health care are lacking in environments which foster maximum independence.

Recommendations of the subcommittees:

- o A range of community services to meet the changing medical, residential, vocational, support and social needs of aging persons with developmental disabilities should be available in integrated settings. The planning for these needs should occur through the IPP process.

13. Some persons with substantial disabilities are denied services because they do not meet the state definition of developmental disabilities.

Recommendations of the subcommittees:

- o The subcommittees recognize the need for integrated, lifelong services to support persons with substantial disabilities who do not otherwise meet the California definition of developmental disabilities. DDS should contract with an independent agency to conduct a study in order to determine the number of Californians not currently eligible for but who would significantly benefit from regional center services.
- o While the subcommittees support the expansion of California's definition of developmental disabilities to include individuals who would benefit from regional center services, it recognizes the potential cost inherent in such an expansion. Therefore, a task force should be established to determine the most effective and prudent method of incremental expansion tied to the availability of necessary funding.
- o A review of regional center eligibility assessment tools is necessary to ensure that an arbitrary denial of services is not occurring to persons who might be otherwise eligible under California's current definition of developmental disabilities. This includes denial based on specific diagnoses such as, but not limited to, "educationally handicapped," as well as denial based solely on one assessment tool such as, but not limited to, IQ testing. This review should include a methodology to ensure that eligibility standards are uniformly applied throughout the state.
- o Additionally, a needs assessment should be conducted for those populations traditionally underserved by regional centers, including but not limited to, persons with epilepsy.

PREVENTION

1. Not enough state resources are being allocated to the prevention of long-term disabilities, which take a tremendous toll from a personal as well as from a financial perspective. There is not a financial commitment from the Administration and Legislature on the importance and priority of programs that reduce the incidence of handicapping conditions.

Recommendations of the subcommittees:

- o A statewide policy, and concomitant resources, should be developed to assure that all pregnant women receive comprehensive perinatal care and all children under five years of age receive health and prevention services, including immunizations.
 - o Prevention goals, consistent with the findings in the "Prevention: 1990" report, should be added to the Lanterman Act.
 - o DDS should develop timeframes to implement the goals of its "Prevention: 1990" report, for use by each regional center.
 - o DHS should provide increased health care outreach to immigrants to identify and prevent outbreaks of contagious diseases that may cause developmental disabilities, such as measles.
2. The general public is not well educated about prevention and high-risk populations.

Recommendations of the subcommittees:

- o The Departments of Health Services, Developmental Services, and Education should undertake collaborative efforts to reach the public with prevention messages on prenatal care, alcohol and drug abuse, seat belt and helmet use, and other topics, through the electronic as well as printed media.
 - o Health curricula in public schools should be expanded to include prevention information, starting in grade school.
3. Prevention programs are not a funding priority.

Recommendations of the subcommittees:

- o A continuing data base of incidence characteristics should be maintained by DDS, to indicate changes in the demographics and the diagnoses of new cases of developmental disabilities, and to justify increased funding. This could be done by developing a childhood disability surveillance system capable of documenting the incidence and prevalence of developmental disabilities, analysis of data, and evaluation of prevention strategies.

- o Regional centers should have lower caseloads for families and infants, to take into consideration the increase of intensity and frequency of services required for the complex medical and social problems of at risk children and families.
- o Some of the larger regional centers need additional resources to provide increased genetic counseling, particularly with non-English speaking persons.

4. Prevention programs lack flexibility necessary to meet changing needs.

Recommendations of the subcommittees:

- o The 36-month age limit for "high risk infants" should be extended, in order to give more time to determine if a child continues to be at significant risk for having a developmental disability, and to close the gap between children of this age and five years old, when they enter the school system. This is particularly important for drug-exposed infants, who may have severe learning problems which may not be diagnosed until after three years of age.
- o Regional centers, in conjunction with assistance from DDS, should routinely inform physicians in their areas about assessments and services for diagnosed cases of developmental disabilities.

5. Early intervention, particularly to new populations such as substance-exposed infants, is crucial to the provision of prevention services that can help the infant or child.

Recommendations of the subcommittees:

- o Regional centers, with financial and technical assistance from DDS, should expand their outreach services to women at risk of having a developmentally delayed child, and to families with children that may require a diagnostic assessment to detect the presence of a developmental disability.
- o To the extent regional centers do not currently have reporting relationships with local health departments, hospital maternity wards and neonatal intensive care units, infant stimulation programs, locally-based pediatricians, and other persons and programs that might first see a woman with a high-risk pregnancy, or a child at risk of developmental delay, these relationships should be developed to ensure timely referral, assessment, and follow-up.

- o Education of physicians is necessary to increase awareness of diagnostic and treatment services for developmental disabilities, and of the need for timely referral to regional centers for assessment.
- o Regional center eligibility criteria should be expanded to reflect the broader Federal eligibility criteria for developmentally disabled children. This would allow children who are chronically ill, who do not have a chromosomal abnormality or seizures, or other state-defined developmental disabilities, to qualify for high-risk prevention programs.

SYSTEMS COORDINATION

1. **Interagency agreements do not encourage or promote systems change, nor do interagency agreements alone guarantee efficiency of service delivery.**

Recommendations of the subcommittees:

- o Good coordination and strong program linkages can sometimes, but not always, be mandated. To do so would require constant modification of the Lanterman Act and other laws, as new programs are developed and old programs are eliminated. Rather, coordination is as much determined by attitude as it is by program mandate. Family members, clients, professionals, and advocates should continue to request systems coordination, within political and service environments that will continue to change.
 - o The components of the developmental disabilities system, including DDS, SELPA's, regional centers, area boards, and community organizations, should undertake ongoing efforts to educate community-based workers, such as bus drivers, law enforcement, medical providers, and others, about the needs of persons with developmental disabilities.
 - o DDS and the State Council on Developmental Disabilities should establish specific goals involving interagency coordination, in their long-range plans to address the availability, accessibility, and quality of health services.
2. **Medical services for persons with developmental disabilities are often fragmented. Medi-Cal, California Children's Services (CCS), and regional center medical services all have differing eligibility standards and offer different benefit levels.**

Recommendations of the subcommittees:

- o CCS eligibility should be broadened to include medical service criteria to prevent further deterioration or disability. A timeline for CCS decision-making, to either approve or deny a service, should be developed, and a CCS fair hearing appeals procedure should be established, including continuation of the services during the appeal ("aid paid pending").
 - o CCS and Medi-Cal should explain the reasons for delays in the approval of purchase of durable medical equipment such as wheelchairs. The programs should be mandated to provide (or deny) such equipment within a specified period of time.
 - o Regional centers should maintain and update lists of medical providers in their geographic areas, who specialize in treating persons with developmental disabilities.
3. In the area of education, there are a number of interagency barriers that prevent the goals of mainstreaming, appropriate educational services, and integrated learning.

Recommendations of the subcommittees:

- o Educational opportunities for all children should be provided in integrated neighborhood schools.
- o The Health and Welfare Agency and the Department of Education should form an inter-agency staff group to examine the degree of differences in eligibility, assessment and diagnostic procedures, service linkages, and common goals in programs and services for persons with developmental disabilities. Alternatively, this job could be conducted by SCDD.
- o The regional center, which is responsible for the development of the individual program plan that addresses a wider range of needs of a developmentally disabled child than the school district, which creates the child's individual education plan, should have ultimate authority to review the IEP to determine whether the IEP goals are consistent with IPP goals. If the goals are inconsistent, the regional center should have authority to require another IEP consultation, to conform the goals. The IEP should be subordinate to the IPP.

- o The Association of Regional Center Agencies should develop more uniform operating methods among the 21 regional centers, regarding the way in which they develop coordination procedures with special education programs.
 - o SELPA's should be given a certain amount of freedom from liability in serving more medically fragile students, under specified circumstances, to address the growing number of medically-fragile children who need education programs.
4. The system permits conflicts over the different monitoring responsibilities of different agencies, in the areas of expectations, processes, and regulations.

Recommendations of the subcommittees:

- o The Departments of Developmental Services, Health Services, and Social Services should educate community care providers about the myriad of regulations and licensing requirements to which their programs are subject.
 - o Licensing requirements should be flexible so as to ensure client needs can be met in safe environments within the community.
 - o A mechanism for resolution of conflicts between regulatory agencies must be developed and regulations must allow for the flexibility necessary to address the individual needs of each client.
5. Inadequate or nonexistent transportation is a pervasive obstacle to appropriate, integrated services.

Recommendations of the subcommittees:

- o Local transportation agencies should be required to reimburse regional centers for transportation costs incurred due to a lack of adequate public transportation.
- o Area boards should instigate proceedings of non-compliance against local transportation agencies when they fail to meet the transportation needs of persons with disabilities.
- o SCDD should explore ways to motivate local transportation agencies to provide adequate transportation services, including making reports to federal funding agencies.

FUNDING

1. There are a number of funding disincentives that discourage least restrictive placements.

Recommendations of the subcommittees:

- o Funding systems need to be developed that will encourage and stimulate flexible support programs to enable families to stay together and adults with developmental disabilities to live as independently as possible.
- o Additional flexibility in funding different levels of care, tailored to specific service delivery needs, is needed to assist families in caring for their developmentally disabled family member.
- o Regional centers should be given the authority to designate new vendors without requiring Departmental approval.
- o Regional centers should have the authority to provide rate exceptions associated with maintaining clients in least restrictive settings, including the cost of client supportive services.
- o Funding the community based service system should be based upon adequate rates and an adequate funding base, to start and continue to provide quality programs to meet the full range of needs of individuals and their families.
- o Budget incentives should be developed to encourage the Department and regional centers to develop and maintain community-based programs, and to use these programs instead of institutions whenever possible.
- o Rigid funding categories and funding requirements should be eliminated if they prevent or discourage the start-up and continuation of creative new programs that will respond to the needs of clients and families.
- o Family members should be given greater incentive and opportunity to participate in both designing and purchasing the services needed by their developmentally disabled sons and daughters. Vouchers for parents, in predetermined or prenegotiated amounts, should be considered as one method of allowing greater family participation and choice in the services purchased for clients.

- o The Departments of Health Services, Developmental Services, and Social Services should earmark a source of funding for community-based residential and day programs that are "marginally operating" for lack of adequate financing, to prevent program closures that would result in clients being placed into more restrictive or inappropriate facilities and programs. Technical assistance, emergency management, and other provisions should be considered as part of an array of options that should be vigorously pursued by the Departments of Developmental Services, Health Services, Social Services, and Rehabilitation, to prevent closure of programs that are acknowledged as providing quality community-based care.
 - o The Lanterman Act should be amended to clarify a high priority for funding of services designed to assist families in caring for their children at home, and those services necessary to prepare and support independent living.
 - o The Department and the regional centers should develop new methods to address projected state and individual regional center deficits in a manner that is least disruptive to clients and their families, other than the current requirement that regional centers transfer funds from their operations budgets to their purchase-of-service budgets when experiencing or anticipating deficits. Regional centers should be given the flexibility to address projected budget shortfalls with more creativity, innovation, and consideration of client and family input.
 - o The Program Development Fund (PDF) should be used in accordance with the intent of the Lanterman Act to establish new community-based programs, rather than to provide subsidies or rate differentials to existing programs. Local area boards and regional centers, with parental input, should have greater determination in the use of PDF expenditures for new programs.
2. **Proposals to supplant state funds with federal funds and parental fees threaten total dollars available for services and would set a precedent conflicting with the intent of the Lanterman Act. Also, the state fails to use all federal money available.**

Recommendations of the subcommittees:

- o California should maximize available federal funding by seeking all relevant funding and waivers consistent with service philosophies embodied in the Lanterman Act.

- o New funding could be obtained to enable more developmentally disabled persons to remain in non-institutional settings. Additionally, federal funding could be obtained to serve special populations that require focused treatment, such as drug babies or AIDS babies.
 - o However, the essential entitlement principles of the Lanterman Act should not be discarded merely in order to obtain additional federal funding; application for waivers or additional funding should include consistency with Lanterman Act principles of least-restrictive alternatives and entitlement.
 - o All federal funding available through waivers, targeted case management, and other federal options should be assessed for their ability to assist families in maintaining the person at home or in community-based settings.
 - o Federal funding should be sought to increase services and reduce caseloads, but should not be used to offset or supplant funding for developmental services.
 - o The Departments of Health Services and Developmental Services should ensure that participation in federal funding programs be considered in terms of the direct benefit to clients and families.
 - o The Department and the State Council on Developmental Disabilities should review all available Medicaid funding programs that allow funding for non-institutional programs, in order to decide which Medicaid program options would yield the greatest benefit to clients and their families.
 - o The Department and Legislature should join forces to lobby Congress and the President to raise the federal cap on the number of persons that can be served in California under the Medicaid home and community-based waiver.
3. **The current budget methodology fails to recognize entitlements and to support all portions of the Lanterman Act. The purchase-of-service (POS) budget for regional centers is especially inadequate. Inappropriate budgeting methodologies lead to yearly shortfalls in the POS budget.**

Recommendations of the subcommittees:

- o Given the entitlement provisions of the Lanterman Act, which have been upheld by the California Supreme Court,

funding should be directed to reflect the right of persons with developmental disabilities to receive services pursuant to their treatment plan.

- o Currently, IPP functions as a prescription for services, rather than an assessment of actual needs, and of services required to meet those needs, as the Lanterman Act originally intended. Only when unmet client needs are identified will the developmental disabilities system be able to project and plan for the services and funding required to meet these needs.
- o At this point, the entitlement provisions in the Lanterman Act are not being met due to limitations on funding. To continue to require regional centers to fund services, when they have not been allocated sufficient funds, produces an unrealistic expectation on the ability of regional centers to meet their mandates without sufficient resources.
- o New allocation methods should be developed that will avoid the annual funding shortfalls experienced by regional centers in their purchase-of-service budgets. These methods must include a reasonable estimate of new caseload, as well as of actual services that will be needed.
- o A separate budget line item should be established for family support services, instead of incorporating these services under the category entitled "Other services." Giving family support services greater visibility as a separate category under regional center purchase-of-service would elevate family support services to the same degree of conceptual parity in importance as residential and day program budgets.
- o The Association of Regional Center Agencies should report to the Legislature on the feasibility of regional centers revising their individual program plan formats, to contain not only references to services that will be purchased or provided for the client, based upon assessed need, but also to refer to services that should be purchased that reflect unmet needs. The Lanterman Act should be amended to allow this format change, if necessary.
- o The Legislature should consider the feasibility of allowing regional centers to "opt out" of specific functions, in the event that budget allocations to regional centers fall far below the ability of the centers to purchase services to meet client needs. An "opt-out" provision could allow the regional centers,

for example, to choose under such conditions to retain the functions of providing intake, assessment, diagnosis, and case management, and to "opt out" of the responsibility for funding purchase of services pursuant to the IPP.

4. **Funding disparities in the developmental services system between allocations to developmental centers and community programs may be a result of ineffective spending resulting in inappropriate placements.**

Recommendations of the subcommittees:

- o Currently, there is a significant disparity between funds allocated to the developmental centers and allocated to community programs. Equity between community and institutional settings, both in allocations to the two systems and in wages to staff working in both types of settings, should be addressed.
- o Rate adjustments and cost-of-living adjustments should be allocated equitably, to community-based programs as well as to developmental centers and to regional centers.
- o The Lanterman Act should be amended to address the principle that wage differentials to direct care staff should reflect the requirements of the job and the qualifications of the worker, rather than the setting in which the service is delivered.
- o Parity and equity in wages between developmental center staff and community-based staff should be enacted to ensure there are no disincentives toward the creation of a stable and quality community system of care.
- o The Legislature and Administration should review the appropriateness of the differential of allocations to developmental centers and community programs, including per-client cost, client outcomes, and ability to provide services to severely handicapped persons in non-institutional settings.
- o The Legislature and the Administration should undertake a fundamental reassessment as to whether the developmental center system is in fact the most cost-effective and least restrictive way of providing services to persons with significant disabilities who currently reside in them.

5. Other generic agencies that serve persons with developmental disabilities do not have requirements, or funding incentives, that will result in providing timely services to qualifying clients.

Recommendations of the subcommittees:

- o Other agencies that provide services to persons with developmental disabilities outside of the DDS funding system must cooperate to assess clients for eligibility, and to provide generic services, in a timely manner.
- o Generic agencies should be required to provide services, within a reasonable amount of time. If the generic agency fails to meet these timelines, then regional centers should be permitted to purchase a service for a qualifying client and to bill the agency for the service.